# IA UPDATE

October 2026

## Welcome

It's been a busy few weeks with IA making headlines for our views on some UK airports' treatment of ostomates and rallying for fairer stoma care. And you can now pre-register for IA's Information Day, 24 April 2027!

October's round-up covers events from around the network, volunteering news and more. Don't forget, we love hearing from you too so please get in touch, whether it's to share your story, give us feedback or let us know about your events: marketing@iasupport.org

## IA's travel stance shared in BBC Wales news story

In recent years, IA has heard from many people living with stomas about humiliating treatment experienced during security screening at UK airports. It prompted IA to launch a dedicated travel survey last year, inviting ostomates to log any negative incidents, with the aim of influencing airport authorities to improve their procedures.



In October, IA was approached by BBC Wales for comment on the recent "degrading" treatment of cancer survivor and ostomate Paul Scanlon at Cardiff Airport, where he says he was made to feel like a criminal by security staff. IA's Chief Executive Lisa Barker shared findings with the news outlet from our travel survey, while IA's Stoma and Pouch Care Specialist Nurse Emma Greenwood offered practical advice for travellers based on both her clinical and personal experience of living with a stoma. Together, they highlighted how greater awareness and consistent support can improve the travel experience for people living with a stoma.
**Read our full story here**.

## IA Trustee Jacqui Sibbald calls for fairer stoma care across Scotland



IA Trustee Jacqui Sibbald has been speaking up for people with a stoma as part of a national push to end the postcode lottery in stoma care in Scotland.

In October, the Scottish Stoma Forum brought together the NHS, Scottish Government, patient groups and industry at Edinburgh's Western General Hospital to discuss the future of stoma services. With around 20,000 people in Scotland living with a stoma, the Forum wants the upcoming reform of health boards to bring a consistent national approach, including fair access to specialist nurses, annual reviews, and patient choice over products and services.



Jacqui (*pictured right*) whose comments featured in *healthandcare.scot* bulletin's coverage of the event, highlighted the emotional as well as physical impact of surgery. She said better access to specialist nurses, peer groups and home visits would make "a huge difference" to patients.
You can **read the full article here**.

# Stoma care open day attended by Norfolk & Suffolk IA




Norfolk & Suffolk IA Chair Jane Griffiths and committee member John Smail (*pictured left*) attended a Stoma Care Open Day on 10 October at The Frank Lee Centre, Cambridge University Hospital.

Jane said: “Lead Clinical Nurse Specialist Anna Brewer and the stoma care team made us feel very welcome. Various companies and charities relating to stomas were in attendance, along with a stand that the stoma care team manned.

“There was a steady intake of visitors, and we were able to provide both support and information to ostomists and their relatives. Several took application forms to join IA.”

# North of Scotland IA’s Stoma Information Day

North of Scotland IA held a successful Stoma Information Day on Saturday 29 August, from 10am-1pm at Curl Aberdeen.



Group Chair Sarah Henry said: “It was a very busy day, attended by 193 people who came along to see the latest ostomy products from product company reps and to seek advice and information from the stoma care team and specialist dietitian from Aberdeen Royal Infirmary. A Bear Named Buttony and Clan Aberdeen Cancer Support offered advice and support alongside members of our committee.

“With no local groups for people with a colostomy or urostomy, we displayed literature from Colostomy UK and the Urostomy Association, which was well received. Refreshments were served in an area just off the main hall which allowed people to meet and have a chat over a cuppa. We were delighted to welcome IA’s Group Relationship Lead Roy Bustin, and appreciated his support of our event.”

# IA member talks to BBC Radio York about life with a stoma

IA member Amber Burnip (*pictured*) spoke to BBC Radio York’s Joanita Musisi on 13 October about her experiences of ulcerative colitis and life with a stoma. The radio opportunity arose through a contact of Amber’s who knew Joanita, and had asked her if she’d be interested in talking to her.



Amber’s candid conversation about the highs and lows from symptoms to post surgery was brilliantly expressed, sharing her challenging climb back to health. She said of her stoma that it “keeps her alive” but that she “doesn’t go for more than a few minutes without thinking about it”, and that taking up Pilates had been a great way for her to regain her strength. Amber’s passion for the exercise has since led to her becoming a Pilates teacher, where she helps others who are seeking gentle ways to regain their fitness.

You can **tune in to hear what Amber had to say** at 39.15 minutes into the BBC York radio show.

# IA Information Day, 24 April 2027

***** PRE-REGISTER YOUR INTEREST HERE *****

## IA Information Day, Saturday 24 April 2027, 9am to 5pm

**Radisson Blu East Midlands Airport, Herald Way, Pegasus Business Park, Derby DE74 2TZ**

We're thrilled to announce that we have reserved a venue for IA's AGM and Information Day 2027. After the wonderful turnout at our 70th anniversary meeting this year, we hope you'll be keen to join us once again for more expert insight in the form of presentations and workshops, and the chance to relax and socialise with friends old and new.

IA's Information Day is *the* event of the year for anyone seeking advice and support on all things ileostomy and internal pouch. Product reps will also be in attendance to showcase the latest innovations in stoma care and management, so don't be shy about approaching them with any questions you may have.









By the close of the event, it is our hope that you return home with renewed confidence, new contacts and stacks of information to support your current stage of health, whether that's pre-surgery anxieties or post-surgery recovery.

Concluding Information Day, our gala dinner at the same venue is a popular way to wind down, followed by live entertainment into the evening. Dancing shoes at the ready!

While it's still early days in our planning, we will release more information very soon, including booking information and *(for company law members and board trustees only)* details of our AGM which will also take place at the Radisson Blu East Midlands Airport on Friday 23 April 2027.

## Pre-register

**You can pre-register your interest in attending Information Day 2027 today at iasupport.org/infoday27. Pre-registering is free and there's no obligation to attend. We'll be in touch in the new year with the full programme and details of how to book your place.**

# Bag, pouch, appliance... what do you call your stoma device?

Recently, some of our members raised whether “bag” is the right way to describe a stoma device. It’s a simple question, but the answer is less straightforward. Emma Greenwood, IA’s Stoma and Pouch Care Specialist Nurse, said: “I’ve researched and considered IA’s response carefully as I’m aware of the importance of the use of language and the impact it can have.



“Why does the word matter? Studies show that stoma surgery can influence body image perception and self-esteem, and research tells us that how we talk about life with a stoma can influence how people feel about themselves. Person-centred care includes the type of language used, which can shape how people feel about their bodies and their condition day to day. Currently, the reality is that stoma -bag, -appliance, and -pouch are used interchangeably and inconsistently by many.”

## Share your thoughts about stoma device terminology in our online survey

To have your say about the terminology you prefer to use to describe your stoma device, please visit bit.ly/4x5CTXL to complete our short online-only survey, which will remain open until 31 December 2026. The results could shape IA’s communications, and we hope to share the findings more widely to help inform how stoma care is discussed across the NHS and beyond.

*There is no requirement to provide your name or other identifying details. IA will update members on how we plan to proceed based on the survey outcome in due course.*

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# Neil Smart Memorial Research Award

In memory of Professor Neil Smart, colorectal surgeon and IA trustee for many years, IA has established a dedicated research award, recognising Neil’s commitment to advancing research and improving patient outcomes through knowledge and collaboration. Funds donated will directly improve quality of life for people living with an ileostomy or an internal pouch.

## Donate online or via Text Giving

iasupport.org/neilsmartaward **OR**

Text NEIL to 70480 to donate £10 OR text NEIL plus donation amount of your choice, e.g.,
NEIL1 to 70480 to donate £1*
NEIL20 to 70480 to donate £20*

**Please ensure you have the bill payer’s permission. Texts will cost the donation amount plus one standard network rate message. Text Giving allows the maximum of £20 per donation subject to maximum of £240 per month per mobile number. IA will receive the cost of your donation less processing fees charged by our third party suppliers. For online payments this is 1.5% (UK cards) of the donation amount plus 20p; for donations via Text Giving this is 5% of the donation amount plus a single monthly payment fee. Fees may be subject to change.*

# Periods and stoma care: survey invitation

After her stoma surgery, Ella Fullard struggled to find underwear that worked with both her stoma and her period protection, and found little practical guidance to help.

“I want to find out whether this is just my experience or something lots of people are dealing with quietly,” said Ella. “Hearing from others will help me understand what people really need.”

If you have a stoma and still have periods, you can take part in Ella’s anonymous survey, which takes about three to five minutes. To receive the link, email Ella at: ecfullard@outlook.com






# Applications open for NHS Patient Entrepreneur Programme

If living with a stoma or internal pouch has sparked an idea that could make life easier for others, the NHS wants to help you make it happen.

The NHS Patient Entrepreneur Programme (PEP) is a free 12-month programme for patients and carers in England who are developing innovations based on their lived experience.

As a patient entrepreneur, you’ll learn how to develop, test and grow your innovation, with expert guidance and a community of fellow innovators behind you. Throughout the year, the support is built around your needs as a patient or carer, so your experience stays at the centre of what you create. *Applications close at 4pm on 20 November 2026.* **Find out more here**.

# IA National Office Christmas closure

IA National Office will be closed for the festive period from close of business on Thurday 24 December 2026 until Monday 4 January 2027. We appreciate your understanding and will respond to any emails or voicemail messages as soon as possible upon our return.



# Free patient webinars from The Patients Association

The Patients Association is an independent charity that has championed the voices of patients across health and social care for more than 60 years. Its free webinars bring patients, healthcare professionals and charities together to explore topics such as shared decision-making, access to care and how the NHS communicates with patients. Every session is recorded, so you can watch whenever it suits you.

**Making decisions together**

The latest webinar, '*Making decisions together: Supporting conversations about bladder and bowel products and services',* addresses patients' concerns that decisions about products may be driven by cost to the NHS rather than by individual needs. Speakers include patients, a clinical nurse specialist, and representatives from the Urostomy Association and Colostomy UK. They share their experiences of accessing the right products and services and explain how shared decision-making enables you and your healthcare professional to make informed choices together.

The webinar also includes a free guide and short animation, co-created with people living with bladder and bowel conditions in partnership with Coloplast. These resources can help you understand your rights, prepare for appointments and speak up for your needs.

**Find out more and watch the latest webinar here** and access a **range of The Patient Association's resources** (and search 'past events').



## IA Group News from Roy Bustin, Group Relationship Lead



**Tayside IA welcomes new Area Co-ordinator**

I am delighted to welcome Catriona Ronald to the volunteer network as the new Area Co-ordinator for Tayside IA. Following a positive meeting with members in Dundee recently, Catriona and I will be working to build a plan of activity in the area.

Catriona (*pictured*) said: "I have a background in software development followed by lecturing in computer studies. I went back to university to change my career later in life and became a Registered Nutritionist, having a great interest in diet after my diagnosis of ulcerative colitis in 2001.

"I joined IA after having an ileostomy followed by a reversal six months later, and now have a J-pouch. After letting my membership lapse, I returned to IA recently to benefit from the wide source of information and support.

"I am now retired and was looking to volunteer and support others in areas where I have some experience. The timing coincided with the push by IA to re-establish an active group in Tayside, so here I am as the new Area Co-Ordinator!"

We are looking for more volunteers in the area to help with the relaunch, so do get in touch if you would like to be involved: roy.bustin@iasupport.org

## Safeguarding support at IA



The safety and wellbeing of everyone involved in IA activities is a priority. If you have any safeguarding concerns arising from an IA meeting, event, activity, or interaction, please contact **IA's Safeguarding Lead, Lisa Barker, on 07831 056055**.

If someone is in immediate danger or needs urgent help, always call 999 first.

IA will be rolling out updated safeguarding training for volunteers in the coming months. Until then, it may be helpful to refresh your knowledge by reading the NCVO guidance, '***What to do if you have immediate concerns'.*** This offers practical advice on responding appropriately and helping to keep people safe.

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## Thank you to our volunteers in Humberside

Towards the end of August, we held a meeting for members at Humberside. During the meeting, the existing committee of volunteers shared their intention of stepping down from their respective roles. We would like to take this opportunity to thank Valerie, Trevor and Edward for their contributions and commitment to supporting members in the area over the years.

With these recent developments, we now have new volunteering opportunities available, and we would welcome your support in helping us to build a thriving network of support again in Humberside.

We are recruiting initially for an Area Co-ordinator to work with us to start to plan activities locally. This is a flexible and rewarding role that would suit somebody who enjoys planning and engaging with members. You will be part of an active network of volunteers who are committed to supporting people with an ileostomy or internal pouch. To find out more, please visit our website.

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## Volunteer network meeting, Tuesday 1 December



Whether you've recently joined us or been an IA volunteer for many years, all are welcome at our final volunteer network meeting of the year. This will be happening online on Tuesday 1 December 2026 at 7pm. It will be a chance to share updates and reflect on the progress we've made this year. You might even see a festive jumper!

The session will happen on Zoom, so let us know if you're planning to attend by emailing volunteering@iasupport.org and we will send you the link to join.